



National Kidney Foundation
Council of Nephrology Social Workers

CNSW Care Planning Resource Toolkit

INTRODUCTION

The Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), published the Final Conditions for Coverage (CfC) for End-Stage Renal Disease (ESRD) Facilities on April 15th, 2008. Most provisions of the CfC became effective on October 14, 2008.

The Council of Nephrology Social Workers (CNSW) established a social work task force to develop resources and tools to assist facilities and social workers in complying with new requirements in the CfC. The following document contains information and tools developed to assist social workers in meeting the new care planning requirements in § 494.90 of the CfC.

This document includes the following sections:

- I. Citation of § 494.90 Condition: Plan of Care (CfC)
- II. Assessment to Plan of Care
- III. Social Work Focused Criteria Care Plan Examples
- IV. NKF/CNSW Outcomes Training Program Interventions
 - A. Phase 1 Interventions
 - i. *Case Example* – using the CNSW Example Patient Assessment for care planning
 - B. Phase 2 Interventions
 - i. *Case Example* – using the KDQOL for care planning
 - C. Phase 3 Interventions
 - i. *Case Example* – using the KDQOL for care planning at the end of life

I. CITATION OF § 494.90 CONDITION: PLAN OF CARE (CfC)

In section 494.90 of the CfC, the Interdisciplinary Team, as defined at § 494.80, must use a comprehensive assessment to develop a Plan of Care.

The Plan of Care must:

- Be individualized
- Specify the services necessary to address the patient's needs, as identified in the assessment
- Include measurable and expected outcomes
- Include estimated timetables to achieve outcomes
- Contain outcomes consistent with current, evidence-based, professionally-accepted, clinical practice standards

Additional Citations of Psychosocial Relevance

(a) *Standard: Development of patient plan of care*

The interdisciplinary team must develop a plan of care for each patient.

The plan of care must address, but not be limited to, the following:

[Items (1) through (5) under this Standard are omitted as not relevant to this discussion.]

(6) Psychosocial status. The interdisciplinary team must provide the necessary monitoring and social work interventions. These include counseling services and referrals for other social services, to assist the patient in achieving and sustaining an appropriate psychosocial status as measured by a standardized mental and physical assessment tool chosen by the social worker, at regular intervals or more frequently, on an as-needed basis.

(7) Modality.

(i) **Home dialysis.** The interdisciplinary team must identify a plan for the patient's home dialysis or explain why the patient is not a candidate for home dialysis.

(ii) **Transplantation status.** When the patient is a transplant referral candidate, the interdisciplinary team must develop plans for pursuing transplantation. The patient's plan of care must include documentation of the—

(A) Plan for transplantation, if the patient accepts the transplantation referral;

(B) Patient's decision, if the patient is a transplantation referral candidate but declines the transplantation referral; or

(C) Reason(s) for the patient's nonreferral as a transplantation candidate as documented in accordance with § 494.80(a)(10).

(8) Rehabilitation status. The interdisciplinary team must assist the patient in achieving and sustaining an appropriate level of productive activity, as desired by the patient, including the educational needs of pediatric patients (patients under the age of 18 years), and make rehabilitation and vocational rehabilitation referrals as appropriate.

(b) *Standard: Implementation of the patient plan of care*

(1) The patient's plan of care must—

(i) Be completed by the interdisciplinary team, including the patient if the patient desires; and

- (ii) Be signed by team members, including the patient or the patient's designee; or, if the patient chooses not to sign the plan of care, this choice must be documented on the plan of care, along with the reason the signature was not provided.
- (2) Implementation of the initial plan of care must begin within the latter of 30 calendar days after admission to the dialysis facility or 13 outpatient hemodialysis sessions beginning with the first outpatient dialysis session. Implementation of monthly or annual updates of the plan of care must be performed within 15 days of the completion of the additional patient assessments specified in § 494.80(d).
- (3) If the expected outcome is not achieved, the interdisciplinary team must adjust the patient's plan of care to achieve the specified goals. When a patient is unable to achieve the desired outcomes, the team must—
 - (i) Adjust the plan of care to reflect the patient's current condition;
 - (ii) Document in the record the reasons why the patient was unable to achieve the goals; and
 - (iii) Implement plan of care changes to address the issues identified in paragraph (b)(3)(ii) of this section.

(c) Standard: Transplantation referral tracking

The interdisciplinary team must—

- (1) **Track** the results of each kidney transplant center referral;
- (2) **Monitor** the status of any facility patients who are on the transplant wait list; and
- (3) **Communicate** with the transplant center regarding patient transplant status at least annually, and when there is a change in transplant candidate status.

(d) Standard: Patient education and training

The patient care plan must include, as applicable, education and training for patients and family members or caregivers or both, in aspects of the dialysis experience, dialysis management, infection prevention and personal care, home dialysis and self-care, health-related quality of life, rehabilitation, transplantation, and the benefits and risks of various vascular access types.

II. ASSESSMENT TO PLAN OF CARE

The completion of a comprehensive interdisciplinary patient assessment is the first step in the care planning process and will generate a list of problems. The care team will create or adjust the plan of care to address the problems identified by the assessment.

The following are example social work focused plans of care. These care plans follow the order of the *Comprehensive Multidisciplinary Patient Assessment (CMPA) Example Questions* developed by NKF, its professional councils, and the American Nephrology Nurses Association (ANNA). The assessment was designed to assist facilities in complying with new requirements in the recently issued Conditions for Coverage (2008) and can be accessed at www.kidney.org/professionals/CNSW/.

Each example care plan includes problems, interventions, and outcomes and is intended to stimulate thought processes. These examples are by no means all encompassing. If you work for a larger dialysis corporation, your organization will have policies in place for how to address interdisciplinary care planning.

These examples may help you with language to use as you become more comfortable with an outcome-driven model of nephrology social work practice (as described later in this document).

III. SOCIAL WORK FOCUSED CRITERIA CARE PLAN EXAMPLES

PROBLEM	INTERVENTION	OUTCOME
Communication Status Section of CMPA		
<p><i>Barrier to patient communicating verbally in English</i></p> <ul style="list-style-type: none"> • Patient not able to communicate in English. • Patient only able to communicate basic needs to staff. 	<p><i>Assess available options for communication</i></p> <ol style="list-style-type: none"> 1. Work with support system to have caregiver present or develop an alternate means of communication for patient. 2. Social worker will work to provide professional interpretative services, either in person or through a phone-based language line. 3. In addition to #2, work toward providing materials to the patient's support system that can be understood and helpful to both the patient and their support system, in caring for patient. <p><i>Timetable: Within __ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Communication of treatment needs is improved to enhance treatment outcome. This is evidenced by:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____
<p><i>Barrier to reading printed material</i></p> <ul style="list-style-type: none"> • Patient is unable to read. • Patient has limited reading ability. • Patient needs alternative reading material formats. 	<p><i>Further assess support system resources and alternative styles of communication.</i></p> <ol style="list-style-type: none"> 1. Care team will verbally review all materials or request a support person in family to review materials with patient. 2. Care team will provide material normally delivered in written format to patient in _____ format. <p><i>Timetable: Within __ days of identified</i></p>	<p><i>Communication of treatment needs is improved to enhance treatment outcome. This is evidenced by:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____

PROBLEM	INTERVENTION	OUTCOME
	<p><i>problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Physical or cognitive barriers are present that affect ability to communicate</i></p> <ul style="list-style-type: none"> • Not able to communicate at all or communication is limited by the following physical/cognitive barrier(s): _____ 	<p><i>Further assess support system resources and alternative styles of communication</i></p> <ol style="list-style-type: none"> 1. Work with support system to have caregiver present or develop an alternate means of communication for patient. This means of communication will be _____. 2. Care team will provide written material in _____ format to the patient. <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Communication of treatment needs is improved to enhance treatment outcome. This is evidenced by:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____
Advance Care Planning Section of CMPA		
<p><i>Advance care planning needed</i></p>	<p><i>Include Advance Care Planning as part of yearly assessment</i></p> <ol style="list-style-type: none"> 1. Follow ethical and corporate guidelines regarding advance care planning. 2. If the facility is unable to honor the patient's advance directives, provide patient with information about alternative treatment facilities that will honor the patient's advance directives. 3. Help patient and support system understand the difference between: 	<p><i>Facility staff, patient and patient's support system verbalize an understanding of advance care planning and other end of life issues, as it relates to patient's wishes. This is evidenced by:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____

PROBLEM	INTERVENTION	OUTCOME
	a. Living will b. Durable power of attorney for healthcare c. Do Not Resuscitate Order at Facility d. Do Not Resuscitate Order in Community <i>Timetable: Within ____ days of admission and yearly thereafter.</i>	
Psychosocial Barriers Section of CMPA		
<i>Insurance status is a barrier to positive treatment outcomes</i>	<i>Provide referrals, educate on use of resources, provide advocacy efforts to assist patient in accessing insurance.</i> 1. Refer to Medicare, Medicaid and/or other insurance. 2. Refer to disability or other entitlement programs. 3. Refer to pharmaceutical assistance programs 4. Educate patient regarding long-term planning and encourage <i>and refer to VR to improve outcomes.</i> <i>Timetable: Within __ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i>	<i>Patient obtains adequate insurance to optimize treatment outcome.</i> <ul style="list-style-type: none"> • Patient obtains copay and/or premium assistance to optimize treatment outcome but understands that criteria for these assistance programs change and that if transplanted, access to some of these programs will no longer be available. • • Patient understands the need to maintain long-term insurance for chronic illness and is able to set <i>realistic goals to progress toward this lifelong goal.</i>
<i>Transportation</i>	<i>Assess patient's mode of transportation to dialysis.</i> 1. If indicated, refer to non emergency medical or public ADA transportation service. 2. Teach patient or support system how	<i>Patient is able to get to and from dialysis and other medical appointments.</i>

PROBLEM	INTERVENTION	OUTCOME
	<p>to use transportation services.</p> <ol style="list-style-type: none"> 3. Teach patient or support system how to file for transportation reimbursement if available. 4. Review patient's understanding of home dialysis options, and assess patient's interest in home dialysis. <p><i>Timetable: Within ____ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Vocational Rehabilitation Status</i></p>	<p><i>Assess patient's vocational rehabilitation, goals and potential.</i></p> <ol style="list-style-type: none"> 1. If currently employed, support patient to remain employed by working with patient, company and dialysis facility proactively and as needed. 2. If patient is currently employed, and an in-center dialysis patient, review options for alternative scheduling with the patient to accommodate his work schedule. If the unit cannot accommodate the patient's work schedule, the patient will be given a list of alternative dialysis units in the area that have alternative scheduling. 3. If patient is not currently employed, assess patient's stabilization to CKD and onset of treatment prior to vocational rehabilitation referral to optimize success of referral. 4. Assess patient's beliefs about and support for working while on dialysis to understand and dispel myths and 	<p><i>Patient will achieve optimal rehabilitation potential as evidenced by:</i></p> <ol style="list-style-type: none"> 1. ____ 2. ____

PROBLEM	INTERVENTION	OUTCOME
	<p>misconceptions</p> <ol style="list-style-type: none"> 5. Assess need for physical therapy, occupational therapy, and exercise program to increase patient's readiness for employment. 6. Review health-related quality of life measurement to assess readiness to pursue rehabilitation goals if patient was assessed to be unstable during initial assessment. Refer as appropriate to vocational rehabilitation resources. <p><i>Timetable: Within 90 days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Social/Environmental Needs</i></p>	<p><i>Assess resources and support system. Assess patient and/or support system's capacity to follow referrals to community or agency programs.</i></p> <ol style="list-style-type: none"> 1. Refer to appropriate resource programs—local, state, and national. 2. Apply for grants, as indicated. 3. Teach patient how to self-advocate. 4. Ongoing case management. <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Patient has adequate resources to adhere to treatment plan, specifically:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____
<p>Mobility Status, ADLs and IADLs, and Physical Rehabilitation Section of CMPA</p>		
<p><i>Compromised ability to care for self or perform activities of daily living (ADL) and</i></p>	<p><i>Assess patient's ability to self-manage care</i></p>	<p><i>With the following support systems in place, patient is adequately able to self-manage at home and is</i></p>

PROBLEM	INTERVENTION	OUTCOME
<p><i>instrumental activities of daily living(IADL)</i></p> <ul style="list-style-type: none"> • Basic activities of daily living consist of these self-care tasks¹: <ol style="list-style-type: none"> a. Bathing, dressing and undressing, eating, transferring from bed to chair and back, voluntarily control of urine/feces, using the toilet, walking (not bedridden) • Instrumental activities of daily living are not necessary for fundamental functioning, but enable the individual to live independently within a community²: <ol style="list-style-type: none"> a. Light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, managing money. 	<p>Identify specific barriers and how these barriers will impact treatment outcomes, such as:</p> <ol style="list-style-type: none"> 1. Treatment attendance 2. Phosphorus control 3. Fluid management 4. Albumin management 5. Nutrition <p>Develop a targeted care plan to support the specific area of need, such as:</p> <ol style="list-style-type: none"> 1. In-home care giver to assist with bathing/dressing and getting ready for treatment 2. Support system and adherence cues for medication management 3. Assess for depression regarding eating patterns, refer to community resources for in-home help or home-delivered meals 4. Refer to Home Health Care and for DME as indicated <p><i>Timetable: Within __ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>able to optimize treatment recommendations:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____
Living Situation Section of CMPA		
<p><i>Patient's living situation requires coordination of care</i></p>	<p><i>Establish coordination of care</i></p> <ol style="list-style-type: none"> 1. The social worker will contact the care facility as part of assessment. 2. The care team will send a copy of treatment log to the care facility following each treatment. 	<p><i>Patient's treatment outcome is improved by case management with living facility including:</i></p> <ol style="list-style-type: none"> 1. _____ 2. _____ 3. _____

PROBLEM	INTERVENTION	OUTCOME
	<p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Patient's living situation is a barrier to positive treatment outcome</i></p>	<p><i>Assess and isolate barriers contributing to problematic living situation</i></p> <p>Depending on the assessment, plan may include interventions such as, but not limited to:</p> <ol style="list-style-type: none"> 1. Family counseling 2. Referral to community housing 3. Referral to homeless shelter programs 4. Referral to domestic violence programs 5. Referral to adult protective services 6. Referral for long-term care assessment 7. Referral for home health care <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Patient has an adequate living situation to promote a positive treatment outcome, i.e. this can be measured by a decrease in stress that seems to be positively reflected in blood pressure control.</i></p>
<p>Support System and Spirituality Section of CMPA</p>		
<p><i>Patient's ability to engage in previously enjoyed recreational activities has decreased due to onset of chronic kidney disease or other medical complications</i></p>	<p><i>Review health-related quality of life measurement</i></p> <p>Isolate patient-perceived barriers to problem.</p> <ol style="list-style-type: none"> 1. Assess for depression 2. Possibly refer for physical therapy, exercise 3. Encourage pursuit of hobbies/activities previously enjoyed 	<p><i>Patient's level of functioning improves, as demonstrated by functional status measure (i.e. health-related quality of life measurement, depression index, etc.)</i></p> <p><i>Patient reports engaging in previously enjoyed hobbies.</i></p> <p><i>"On a scale of 1 to 5, how much do you feel you have gotten back into life over the last month?"</i></p>

PROBLEM	INTERVENTION	OUTCOME
	<ol style="list-style-type: none"> 4. Assess possible support extensions 5. Assess strengths and explore how to use these <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Patient perceives inadequate support which impacts treatment outcome</i></p>	<p><i>Focused psychosocial reassessment to include, but not limited to:</i></p> <ol style="list-style-type: none"> 1. Social support system 2. Family/marital problems 3. Abus/neglect issues 4. Conflicted relationship with health care team 5. Are resources still in place to achieve targeted treatment outcome? 6. Make appropriate referrals as indicated. <p><i>Establish peer contacts if possible, i.e.</i></p> <ol style="list-style-type: none"> 1. Bring patient into class setting at dialysis center if mental status allows. 2. Encourage support from worship center if patient allows. 3. Ongoing case management. <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Possible outcome goals might be:</i> <i>Patient goal to gain less than 3 kg between treatments has been achieved</i> <i>Patient feels increased support as rated on a scale of 1 to 5 from December 1 to January 15.</i> <i>Patient completed in-center psychoeducation class with other dialysis patients focusing on conflict resolution. Patient reports increased support from dialysis peers.</i></p>
<p><i>Spiritual or cultural practices or restrictions that the health care team may not understand can impact treatment</i></p>	<p><i>Educate and collaborate with patient and staff:</i></p>	<p><i>Team is better able to assist patient in achieving medical recommendations after understanding the person-in-environment fit.</i></p>

PROBLEM	INTERVENTION	OUTCOME
<p><i>outcomes.</i></p>	<ol style="list-style-type: none"> 1. Help patient to understand the importance of being an active and central part of the care planning process. 2. Be the liaison to the health care team in modifying the treatment plan and in improving understanding of patient/family needs and concerns with the team. 3. Provide counseling for adaptation to treatment for kidney disease and lifestyle fit, using systems theory. <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<ul style="list-style-type: none"> • Patient achieves better treatment outcomes. • Patient feels more empowered on a scale of 1 to 5. • Patient's family feels engaged in treatment and, therefore, patient feels supported.
<p><i>Cognitive Patterns & Cognitive Skills for Daily Decision-making Section of CMPA</i></p>		
<p><i>Change in cognitive status relating to short-term memory or long-term memory that will impact treatment outcome</i></p>	<p>Focused Reassessment</p> <ol style="list-style-type: none"> 1. Assess for patient's ability to make decisions regarding daily life: <ol style="list-style-type: none"> a. Independent b. Modified independence (some difficulty in new situations) c. Moderately impaired (requires assistance in decision making) d. Severely impaired (never/rarely makes decisions) 2. Assess how patient's ability to make decisions impact treatment outcomes? 3. Assess for knowledge deficits 	<p><i>Patient/support system verbalize understanding of treatment plan</i></p> <ul style="list-style-type: none"> • Patient is able to adhere to treatment plan to progress toward positive treatment outcome. • Patient has appropriate care to meet changing needs.

PROBLEM	INTERVENTION	OUTCOME
	<p>Create Health Support Partners</p> <ol style="list-style-type: none"> 1. Stabilize roles in relationships that already exist 2. Help patient and family establish new support systems as needed 3. Understand patient and support system concerns and relate these to team for support 4. Review quality of life measurement and incorporate into care planning. 5. At some point, team may hold discussion of end of life care with patient and support system. <p><i>Timetable: Within 90 days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	
<p><i>Mental health issues related to adaptation to chronic illness and treatment are impacting treatment outcomes</i></p>	<ul style="list-style-type: none"> • Assess for depression using validated assessment tool. • Assess for patient barriers to referral for community mental health counseling. • Review health-related quality of life measurement and incorporate review into care planning. • Refer to dialysis facility offered classes or groups. • If necessary, refer to community resource(s). <p><i>Timetable: Within 90 days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Patient has a better understanding of living with chronic kidney disease and how to use this knowledge for self-management of the disease process throughout the life course of kidney disease</i></p> <ul style="list-style-type: none"> • Patient reports stronger senses of support from support system. • Patient has an improved self-illness schema. • Patient's increased knowledge of the disease process and self-management, improved support system and improved self-illness schema lead to improved treatment outcomes. • Health-related quality of life measurement reflects improvement in_____.

PROBLEM	INTERVENTION	OUTCOME
<p><i>Mental health issues are not related to impaired adjustment to kidney failure and treatment</i></p> <ul style="list-style-type: none"> • Pre-existing psychiatric disorder • Organic brain disorder • Mental retardation • Substance abuse 	<ul style="list-style-type: none"> • Review previous mental health history as well as family mental health history. • Collaborate with current mental health providers, if existing. • Assess for current mental health issues. <ul style="list-style-type: none"> a. Use standardized and validated tools. b. Communicate all issues to team for best care of patient. c. Review effectiveness, side effects, and dialysis of medications with physicians to better understand patient history. • Assess for patient barriers to referral community resources. • Provide brief counseling to patient in dialysis clinic. • Refer to counseling and other resources in the community. • Provide counseling, education and support to caregiver regarding roles / responsibilities. <p><i>Timetable: Within 90 days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<p><i>Patient has improved adherence to treatment recommendations as a result of assessment and targeted interventions, i.e.</i></p> <ul style="list-style-type: none"> • Patient is able to receive entire prescribed treatment. • Patient and/or support system have system in place to remind them to come to treatment 3 times a week or to do all dialysis treatments as prescribed at home. • Family is coping better with treatment-related stress of patient and is better able to support patient. • Patient is seeking treatment for mental health issues (<i>i.e.</i> substance abuse).
Rehabilitation Goals Section of CMPA		
<ul style="list-style-type: none"> • Decreased physical and/or mental functioning • Break in employment due to chronic kidney disease and treatment 	<ul style="list-style-type: none"> • Assess patient's current physical and mental functioning (<i>i.e.</i>, health-related quality of life measurement). • Assess patient's current rehabilitation status. 	<ul style="list-style-type: none"> • Patient has progressed toward improved self-management. • Patient has improved functional status, as noted on health-related quality of life measurement survey.

PROBLEM	INTERVENTION	OUTCOME
<ul style="list-style-type: none"> • Need for training or job placement 	<ul style="list-style-type: none"> • Assess patient's history (e.g. paid work, volunteer, homemaker, student). • Assess patient's rehabilitation goals (present, future). • Assess patient's rehabilitation potential. • Based on outcome of assessment, refer patient to appropriate community resource to progress toward rehabilitation goal. • Advocate with community agencies to help patient obtain desired services as needed. <p><i>Timetable: Within ___ days of identified problem, problem will be ameliorated, resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i></p>	<ul style="list-style-type: none"> • Patient has met rehabilitation goal of _____
Self-Management & Level of Participation in Care Section of CMPA		
<p><i>Patient/support system is having difficulty with self-management</i></p> <ul style="list-style-type: none"> • Patient does not verbalize awareness of all treatment options. • Patient is not internalizing information provided regarding medical recommendations. • Patient is having trouble speaking with a member(s) of the treatment team. 	<p>Assess learning style and capacity to learn.</p> <ol style="list-style-type: none"> 1. Use to plan intervention and ongoing care. 2. Offer hope and encouragement. 3. Conduct a needs assessment. 4. Connect with a peer, if appropriate and possible. 5. Support patient/family involvement in care. 6. Partner with patient in care to speak with other team members, as indicated. <p><i>Timetable: Within 90 days of identified problem, problem will be ameliorated,</i></p>	<p><i>Increased patient self-management (adherence) to medical recommendations as seen by:</i></p> <ul style="list-style-type: none"> • Decreased fluid gains between treatments • Decreased missed treatments • Better blood pressure control • Better phosphorus control • Improved laboratory values • _____

PROBLEM	INTERVENTION	OUTCOME
	<i>resolved or documentation will state intervening reasons for no resolution and revised treatment plan.</i>	
Preferences in Home Dialysis Section of CMPA		
Patient is unaware of home dialysis (peritoneal dialysis and/or home Hemodialysis) as a treatment option.	<p><i>Provide education to every patient on all treatment options (and where options can be found in the area if the facility does not offer all options) within the first 30 days of treatment unless unstable or medically ineligible.</i></p> <p><i>Timetable:</i></p> <ol style="list-style-type: none"> <i>1. Within 30 days of admission treatment to facility</i> <i>2. Every 12 months or as patient needs change</i> 	<i>Patient is aware of all treatment options and has decided on the best fit for his lifestyle. Patient is empowered to better self-manage medical recommendations.</i>
Interest and Suitability for Transplant Section of CMPA		
Patient is unaware of how to pursue transplant as a treatment option.	<p><i>Provide education to every patient on all treatment options within the first 30 days of treatment unless unstable or medically ineligible.</i></p> <p><i>Assist dialysis facility transplant coordinator as indicated to assure that patient receives transplant application for the hospital of his choice</i></p> <p><i>Assist patient in advocacy efforts toward the goal of transplant.</i></p> <p><i>Timetable:</i></p> <ol style="list-style-type: none"> <i>1. Within 30 days of admission treatment to facility</i> <i>2. Every 12 months</i> 	<i>Patient is referred to transplant center for evaluation or self-refers for evaluation.</i>

PROBLEM	INTERVENTION	OUTCOME
<p><i>Impaired adjustment to treatment</i></p> <ul style="list-style-type: none"> • Depression/anxiety/hostility • Family/marital/relationship problems related to chronic disease and treatment • Substance abuse • Sexual problems 	<p><i>Provide counseling and referral services to enhance adjustment to treatment</i></p> <ul style="list-style-type: none"> • Provide individual or group counseling to patient in dialysis clinic. • Refer patient to psychiatrist to assess need for psychotropic medication. • Provide counseling to patient/partner in the dialysis clinic. • Refer patient/family to community counseling services. • Refer to alcohol or drug treatment program. • Refer to MD to rule out physiological etiology or to assess for medication needs. 	<p><i>Patient demonstrates increased ability to cope with disease and treatment</i></p> <ul style="list-style-type: none"> • Patient demonstrates decreased symptoms of depression/anxiety/hostility • Patient shows improved score on depression/anxiety/hostility screening survey • Patient/family verbalizes reduced problems at home • Patient scores higher on instrument measuring health-related quality of life • Patient completes alcohol/drug treatment program and maintains sobriety • Patient verbalizes improvement in sexual functioning
<p><i>Relationship/social network problems</i></p> <ul style="list-style-type: none"> • Inadequate social support system causing patient to feel isolated and alone • Family/marital problems not related to chronic disease and treatment • Neglect/maltreatment (child, adult, elderly) • Conflicted relationship with health care team 	<p><i>Provide counseling, referral and mediation to resolve problems</i></p> <ul style="list-style-type: none"> • Provide supportive counseling in the dialysis clinic. • Refer to services within the community, such as support groups, senior centers, volunteer activities, etc. • Provide counseling to patient/partner in the dialysis clinic. • Refer patient/family to community counseling services. • Refer to child/adult protective services. • Refer to community resources. • Provide mediation services to improve patient/family relationship with health care team. 	<p><i>Patient/family verbalize reduction in problems</i> <i>Patient verbalizes feeling less isolated</i></p> <ul style="list-style-type: none"> • Patient participates in supportive community programs. • Patient scores higher on instrument measuring perceived social support. • Patient/family reports reduced problems at home. • Patient and family living in safe environment. No evidence of abuse/neglect noted by dialysis staff. • Reduced incident of conflicts reported between staff - and patient and/or family.

PROBLEM	INTERVENTION	OUTCOME
<p><i>Psychiatric problems not related to impaired adjustment to treatment</i></p> <ul style="list-style-type: none"> • Pre-existing psychiatric disorder • Organic brain disorder • Mental retardation 	<ul style="list-style-type: none"> • Provide counseling to patient in dialysis clinic. • Refer to community counseling resources. • Provide counseling to family regarding caregiver role and responsibilities. • Refer family to community resources for caregiver support. 	<p><i>Patient demonstrates increased ability to cope with psychiatric problems</i></p> <ul style="list-style-type: none"> • Family demonstrates less stress related to caring for patient.

¹McDowell, I., and Newell, C. (1996). *Measuring Health: A Guide to Rating Scales and Questionnaires*, 2nd edition. New York: Oxford University Press

²Bookman, A., Harrington, M., Pass, L., & Reisner, E. (2007). *Family Caregiver Handbook*. Cambridge, MA: Massachusetts Institute of Technology.

³NASW/CNSW Clinical Indicators, 1994.

IV. NKF/CNSW OUTCOMES TRAINING PROGRAM INTERVENTIONS

Introduction to Outcomes Training Program

The National Kidney Foundation's Council of Nephrology Social Workers (CNSW) has supported and promoted a social work Outcomes-Driven Practice Model for a number of years. The core of this model is a training program entitled *Refocusing Nephrology Social Work: An Outcomes Training Program (OTP)*. This model supports the expanded nephrology social work role in improving treatment outcomes for patients with CKD and focuses on training social workers to provide interventions that promote improvement toward measurable outcomes.

With the new ESRD Conditions for Coverage, social work plans of care must include “measurable and expected outcomes.” OTP provides the necessary tools and training for social workers to successfully meet this challenge.

The following resources are a portion of the handouts that are part of a comprehensive workshop on the Outcomes-Driven Practice Model available to nephrology social workers. Social workers are encouraged to learn more about this practice model by:

- Attending the yearly pre-conference workshop offered at the National Kidney Foundations Spring Clinical Meetings (find out more at <http://www.kidney.org/news/meetings/clinical/>).
- Accessing some of the training modules online at the CNSW web site http://www.kidney.org/professionals/CNSW/sub_meetings.cfm.
- Hosting a regional CNSW Local Chapter training.

The following pages provide example social work interventions. These interventions are organized to reflect one theoretical model of patient adjustment to chronic kidney disease.

This adjustment model theorizes that patients with CKD go through the following phases of adjustment, and require specific social work interventions at each phase:

- Pre-Illness
- Pre-Renal Replacement Therapy (RRT)
- **RRT Phase One “INITIATION OF TREATMENT: CRISIS”**
- **RRT Phase two “CHRONIC FLUCTUATING ILLNESS”**
- **RRT Phase Three “PHYSICAL DECLINE AND DEATH”**

The social work example interventions are provided for Phases One, Two, and Three of the model—the most likely period of social work involvement.

NEPHROLOGY SOCIAL WORK INTERVENTIONS ADJUSTMENT: PHASE ONE

“INITIATION OF TREATMENT: CRISIS”

Phase One Intervention Goals:

- * *Emotional and physical stabilization*
- * *Family/support system stabilization*
- * *Disease knowledge*
- * *Trust*
- * *Hope*

INITIAL SOCIAL WORK INTERVENTIONS:

- Consider pre-dialysis education or a telephone call to the patient beginning RRT (home or hospital) to disarm tension, assist with modality selection and bridge patient and family to treatment center.
- Inquire as to patient's/family's most current concerns or fears upon first contact.
- Introduce the diverse role of the social worker (introduce the five-point ongoing assessment that s/he can expect from you)
 - Disease management
 - Health-related quality of life
 - Functional rehabilitation/continuation of life goals
 - Adjustment of family and friends
 - Satisfaction with care.
- Allow patient and family to debrief the course of events leading to diagnosis and initiation of treatment. Observe for status-post anticipatory grief or trauma-like reaction.
- Explain your plan, when things settle medically, to work as a partner to ensure his/her adjustment and health-related quality of life.
- Explain the value of a family meeting and plan together to hold one to answer the questions and address the concerns of family members/significant others with the patient present.

SOCIAL WORK ASSESSMENT INTERVENTIONS

- Assess patient's perception of his/her pre-illness life functioning (this becomes a baseline measure of pre-morbid developmental functioning).
- Assess patient's perception of how s/he thinks s/he will adjust to this new life challenge. Have patient identify how s/he might be likely to know if s/he is growing more overwhelmed or depressed (this is a screener for locus of control/early illness schema and helps both you and the patient remain a team in monitoring their adjustment).
- Assess for cognitive deficits/altered mental status (learning barrier)

- Assess patient's early understanding of and concerns regarding dietary, treatment and fluid, and lifestyle restrictions (indicating early need for skill building).
- Assess patient and family members learning style/preferences (literacy/language and most effective presentation of educational materials).
- Assess patient's history of depressed or anxious mood. Educate patient regarding the need to monitor for depression, which can occur in up to 40% of patients with kidney disease but is easily treatable.
- Assess patient's previous use of psychotropic medications for sleep, depression or "nerves" (this could indicate the need for early evaluation for medications to prevent a mood disorder episode which could impact health behavior).
- Assess patient's pre-illness role(s) within the family system (this becomes your baseline family engagement measure). Assess who patient has relied on most within the family system and his/her assessment of how all family members might view his/her new illness. Assess cultural views of illness and treatment.
- Assess for cultural views toward illness and treatment (trust/alternative healing beliefs/collective family decision making/fatalism-locus of control).

PROVIDE PSYCHOEDUCATION TO THE PATIENT IN THESE AREAS:

- What s/he might expect emotionally during this time (feeling states/fears/numbness).
- Things to keep in mind and do "right now" (i.e. no big decisions).
- How to guard against catastrophic thinking (reframe thoughts such as "my life is over" and "I'll never be free again") to shape more positive illness schema.
- How patient can explain to others about his/her new illness.
- What his/her family might be going through right now and how they can all work together in their adjustment to CKD.
- Things to contact the SW about (i.e. insurance stress; job decisions; define typical fears, concerns of new patients; give examples/share stories of other new patients).
- The availability of other patient mentors that are willing to call him/her to answer questions and guide him during this period.
- The culture of the dialysis clinic—how it all works, what s/he can expect from the clinic environment, the role of the various team members.

HOLD A FAMILY MEETING WITH PATIENT TO DO THE FOLLOWING:

- Explain the role of the social worker (five-fingers + resource consultant).
- Help the patient explore for each family member's greatest concerns and provide information to reduce their fears.
- Explain that, in the family system, CKD can be like an "involuntary adoption of a new family member" or an "unwanted guest that never leaves". At times it will be a nuisance and will drain the attention and resources of the family but that, eventually, the family can learn to work around it and find a new balance. Discuss each family member's feelings toward the new family addition.

- Explain the disease behavior (initial period of stabilization and then difficult to predict ups and downs). Prescribe family activity and normalization on the “good days” and patience on the “difficult days”. Teach the patient and family how to “scale” so they have a language to understand and communicate the ups and downs of the illness. Explain that fluctuations in health status may be less on one treatment compared to another and may vary from patient-to-patient.
- Discuss how some family activities may have to continue without patient, and how they can connect these to the patient (discuss survivor’s guilt as normal).
- Explain outcome variables (NKF K/DOQI: HD and PD Adequacy, Anemia, Nutrition, Vascular Access); Cardiovascular Health (Fluid, Tx. and Medication, Adherence and Lifestyle Behaviors).
- Explain role of family support (Positive vs. Critical Support).
- Differentiate co-dependency from support.
- Explain depression risk and how to screen for it (mood, withdrawal, hopelessness).
- If the patient requires heavy care, talk openly about the risk of caregiver burnout and the importance of caregiver and self-care plans.
- Explore how current family roles have been reassigned for the short-term initial adjustment period and how the family should expect the patient to return to as many of these as possible after a period of stabilization.
- Ask the patient to let the family know how they should bring forward concerns regarding his/her illness (consider prescribing family meeting where they simply ask the question “how did we all do this week and does anyone have any concerns?”)
- Explain to the family the issue of SW/patient confidentiality and that you must have patient’s permission to share specific information about him/her to family.
- Schedule follow-up family meeting in three months from the date of this meeting.
- Guide family in contacting you should they observe any increase in family tension, depression or other questions needing social work consultation.
- Informally quiz patient’s and families’ understanding of the illness, the treatment regime and the impact of adherence/non-adherence on treatment outcomes.

CONSIDER THESE TYPES OF OUTCOME MEASUREMENTS TO ASSESS THE EFFECTIVENESS OF YOUR PHASE ONE INTERVENTIONS:

- Collect secondary data: actual treatment counts (missed and shortened tx.’s), fluid gains, lab values, nutritional status and nursing or patient perceived medication compliance.
- Use scaling questions for patient/family regarding previously identified fears/concerns.
- Assess family communication behavior: the ability to identify, tolerate and discuss problems and evidence active problem-solving behavior without unnecessary conflict.
- Open-ended questions to measure efficacy and hope: (“How hopeful are you that you can manage this new illness in your life?”) and locus of control: (“Are you hopeful you can influence how things go?”) can help us begin to assess for the emotional and cognitive skills that may need to be strengthened in Phase II of Adjustment to illness to enhance long-term treatment outcomes.

- Assess patient/family trust in and satisfaction with care with the following types of questions:
 - “What are we doing that you like here and what could we do better?”
 - “Are you getting enough time with the staff and physician?”
 - “Are there any questions that have not been answered?”
 - “What types of things does the staff do to make you feel cared about here?”

ADJUSTMENT: PHASE ONE

Case Example—Using the Example Questions of the CMPA

Situation

Jane Doe is a 40-year-old, married, mother of two. She was employed part time prior to initiation of dialysis and was a community volunteer; she is uncertain whether she will return to work. Her husband describes her as a “Type A personality” and the patient is a self-admitted “control freak.” She had advance knowledge of her kidney disease and was planning and progressing toward pre-emptive living donor transplant but she needed to begin dialysis before a transplant could occur. Patient is described by her nephrologist as very capable and compliant with medical directions. Ms. Doe describes increasing anxiety and depression in advance of dialysis for which she has not sought treatment; she is unable to complete treatments due to anxiety.

The following example care plans refer to problems identified by specific questions in the *Comprehensive Multidisciplinary Patient Assessment (CMPA) Example Questions* developed by NKF, its professional councils, and the American Nephrology Nurses Association (ANNA).

The assessment can be accessed at www.kidney.org/professionals/CNSW/.

ADJUSTMENT: PHASE ONE

Case Example—Care Plan

PROBLEM	INTERVENTION	OUTCOME
Advance Care Planning		
<p>Refer to CMPA section AP1a (page 20). Advance care planning indicated and desired by patient.</p>	<p>1. Help patient and support system understand the difference between</p> <ol style="list-style-type: none"> a. Living Will b. Advance Directive c. Durable power of attorney for healthcare d. Do Not Resuscitate Order at Facility e. Do Not Resuscitate Order in Community <p>Timetable: Within 90 days of admission and yearly thereafter.</p>	<p>Patient and patient's support system verbalize an understanding of advance care planning.</p> <p>Facility staff verbalizes an understanding of patient's decision-making regarding end of life issue and are able to accommodate patient wishes.</p> <p>This is evidenced by: Patient has completed advance directive. Advance Directive was reviewed and approved by facility Medical Director, Attending Nephrologist and facility manager.</p>
Rehabilitation Goals		
<p>Refer to CMPA section R1 (page 29). Employment Status – patient is on medical leave of absence from part-time employment and undecided about returning to employment.</p>	<p>1. Assist patient with goal setting and decision-making.</p> <p>2. If patient desires to resume/continue working, support patient by working with patient, employer and dialysis facility proactively and as needed.</p> <p>Timetable: Within 90 days of identified problem, problem will be ameliorated or resolved.</p>	<p>Patient will achieve optimal rehabilitation potential as evidenced by patient satisfaction with quality and quantity of activity.</p>

Support System and Spirituality		
<p>Refer to CMPA section S4 and S7 (page 24) Patient perceives inadequate support</p>	<p>Focused psychosocial reassessment to include, but not limited to:</p> <ol style="list-style-type: none"> 1. Social support system 2. Family/marital problems 3. Abuse/neglect issues 4. Make appropriate referrals as indicated. <p>Teach patient how to explain to others about her new illness. Establish peer contacts if possible.</p> <p>Timetable: Within 90 days of identified problem, problem will be ameliorated or resolved.</p>	<p>Patient will report increased feeling of support over next 3 months.</p>
Cognitive Patterns, Cognitive Skills for Daily Decision-making, and Mental Health Status		
<p>Refer to CMPA sections C4b (page 26) and M6 (page 28) and M9 (page 29) Mental health issues related to adaptation to chronic illness and treatment are impacting treatment outcomes. Patient is unable to complete 50% of treatments due to anxiety. Patient describes depressed mood and signs/symptoms of depression.</p>	<ol style="list-style-type: none"> 1. Teach patient techniques for managing anxiety during treatment. 2. Assess for depression using validated assessment tool. 3. Teach patient about risk for depression and how to self-monitor for signs of depression. 4. Teach patient to develop a positive illness schema, and to guard against catastrophic thinking. 5. Refer to outpatient mental health program to assess for medication needs. <p>Timetable: Within 90 days of identified problem, problem will be ameliorated or resolved</p>	<p>Patient is able to complete dialysis treatments.</p> <p>Patient describes decrease in signs/symptoms of depression.</p>

Preferences in Home Dialysis		
<p>Refer to CMPA sections HD3 & HD4 (page 32) <i>Patient is aware of home dialysis as a treatment option but is not interested at present; expects kidney transplant in near future.</i></p>	<p><i>No intervention required at present.</i></p>	<p><i>Patient is aware of all treatment options and has decided on the best fit for her lifestyle.</i></p>
Interest and Suitability for Transplant		
<p>Refer to CMPA sections T1-T5 (page 32-33) <i>Patient is waitlisted for deceased donor transplant. Friends and extended family members are undergoing evaluation to establish suitability for living donation.</i></p>	<ol style="list-style-type: none"> <i>1. Assist dialysis facility transplant coordinator, as indicated, to facilitate communication with transplant center coordinator to assure that patient is informed about transplant status</i> <i>2. Evaluate whether patient's expectations for transplantation are realistic.</i> <i>3. Educate patient about benefits/burdens of transplantation, need to follow the treatment plan, and costs of care and consequences if treatment plan is not followed.</i> 	<p><i>Patient is referred to transplant center and awaiting transplant.</i></p>

NEPHROLOGY SOCIAL WORK INTERVENTIONS ADJUSTMENT: PHASE TWO

“CHRONIC FLUCTUATING ILLNESS”

Phase Two Intervention Goals:

- * Acceptance and Emotional adjustment
- * Disease Management (self-care)
- * Affect Management
- * Self-Esteem/Positive Self-Illness Schema
- * Rehabilitation/Developmental Progression
- * Health-related Quality of Life

INITIAL SOCIAL WORK INTERVENTIONS:

- Identify for the patient the movement into phase two of adjustment and the overall goals of your contact as a social worker (repeat five point assessment at least quarterly with patient helping to assess)
- Discuss with patient his/her experience with CKD treatment and the prescribed fluid, medication and/or dietary behaviors (see patient questionnaire) Explain to the patient the importance of getting a strong start to managing his/her disease and the restrictions and how it will greatly impact his/her sense of living better and will also help him/her prevent CVD and live longer.
- Consider a referral to a “Healthy Start” or “Living Better” type of discussion for the patient and his/her family so they can get a fuller understanding of how survival and health-related quality of life are impacted by how closely s/he follows the treatment plan and get new ideas and tools for managing kidney failure.
- Explain to patient the common emotional experiences of this transition:
 - *Grief over the way things used to be before the illness*
 - *Concern about not feeling capable of returning to activity due to lethargy*
 - *Anger toward how restrictive the treatment is*
 - *Just “getting through” each day rather than looking ahead to life/planning*
 - *Fear of being a physical or emotional burden to loved ones*
 - *Feeling disabled and no longer fitting in*
 - *Feeling not worth as much as a person now that s/he is ill*
 - *Feelings of depression/anxiety*

ASK ABOUT ANY OF THESE AND MONITOR THEM AS BARRIERS WITH “SCALING”
- Discuss with the patient that sometimes these thoughts can indicate a potential onset of depression. Help the patient know that s/he may not be able to identify their own depression, because it feels so much like the illness of kidney disease, but that it is important that we screen for it, prevent it and when it comes, work with it as much as

possible because it will interfere with his/her rehabilitation, health-related quality of life, family life, ability to manage kidney disease and overall survival. Provide education about depression.

- Explain that if depression begins to arise, there are many things that you and s/he can do to address it. Describe the role of the nephrologist/psychiatrist in prescribing a safe, non-addictive depression medication and your role of working with support and cognitive aspects of depression. Ask permission to help the patient monitor for depression.
- Begin to choose activities from the list of SW Interventions for Depression that we will discuss in the Specialty Issues section to assist the patient in shaping a more positive self-illness schema, reduce the risk of depression and improve health-related quality of life and survival. Consider depression a serious and urgent barrier to the patient continuing to medically stabilize and adjust. If depression is not treated, your efforts to move forward with rehabilitation interventions could be resisted.
- Educate regarding the value of HRQOL measurement (as a screener for depression and also a tool to help rehabilitate the patient and ensure HRQOL).
- Discuss with the patient where, as the new illness stabilizes, s/he is at developmentally. Share Erickson's model of life course. Do a linear lifeline (|—|-----|-----|—|) and have him share where s/he has been and identify where s/he would still like to go. Help the patient identify what might be in the way. This discussion can help the patient reclaim pre-illness identity, and regain a sense of emotional and existential continuity in the face of the illness, where s/he, like always, sets developmental goals, and steps back into life. Teach the patient to prepare to "pause" with the ups and downs of the illness.
- Examine the patient's satisfaction with his/her care from their medical team. Explain to the patient that his/her comfort with the facility and the staff and his/her physician has an impact on the medical course of his/her disease as well as his/her adjustment to living with it. Assess whether training is needed in assertion, problem-solving. Explain mediation services.

HOLD A MARITAL SUPPORT MEETING

- Prior to the meeting help the patient assess how s/he thinks his/her spouse/significant other is adjusting to his/her illness and how the illness has changed the marriage. Offer to invite the spouse in to talk with you and s/he to ask that question and talk a while. Explain that these types of meetings often prevent marital problems from developing in marriages where one person has an illness. The following questions could be discussed at such a meeting:
 - *What was their favorite part of the marriage prior to the illness and has a sense of that part returned? If not, why?*
 - *Have they openly talked about how each of them was doing emotionally with the illness? Have they grieved together? If not, why?*
 - *Have they experienced a change in their sexual life? (Provide psychoeducation here and encourage communication)*
 - *How have their roles been defined with regard to managing the illness? Is this working? Would they like to change anything?*
 - *What would they hope for the marriage now that phase I of the illness has stabilized?*

The following can also be done at the marital support meeting:

- *Provide psychoeducation: discuss the risk of “marital depression” and “sexual and emotional disengagement” as their marriage experiences the ups and downs of the illness. Suggest they meet with you at least annually.*
 - *Explain the role of belongingness support in treatment outcomes.*
 - *Discuss the risk of depression and allow the patient to openly invite the spouse to help observe for it.*
 - *Prescribe marital behaviors that return them to the things they listed in the question about what they loved most (Alternate Caring Days/Dating).*
 - *Instruct the patient and spouse on how to hold a family roundtable discussion with other members of their family to discuss how things are going with regard to their understanding of the illness/their concerns.*
- Help patient assess how s/he thinks each member of his/her family or support system has adjusted to his/her illness and where their concerns may lie. Evaluate with the patient his/her sense of connectedness with family or others and the role of social support in his/her ability to live well and live long. (Belongingness support/Self-Esteem support/Appraisal support/Tangible)
 - If the patient is isolated, consider patient outreach, mentoring or group.
 - Explain that you would like to hold a meeting now and perhaps every year with family/significant others to do the following things to support the family’s ongoing adjustment.

HOLD A FAMILY MEETING TO DO THE FOLLOWING:

- Have the patient participate in thanking the family for attending the meeting to help in their management of and adjustment to the illness. Invite the family to speak openly about how they think things are going.
- Have family members/significant others describe what has been going well and identify any current concerns.
- Explore how the family thinks the family system has changed and what is good and bad about that (listen for problems still needing resolution).
- Monitor the meeting for family stress and normalize that feeling as much as possible. Ask them how they each know they are under stress. Consider referring long-standing problems to a mental health clinician, while continuing to address the family’s adjustment to the illness.
- Identify unmet needs in the family system and help the family identify them.
- Explain the movement of the family into adjustment phase II and the goals of that phase, as well as how you will work to support the patient and family reaching those goals.
- Ask the family what their hopes are for this new phase.
- Explain family activities and behaviors that can be helpful to the patient in managing his/her disease:
 - *Encouragement to return to activity (belongingness /exercise buddy)*

- *Positive instead of critical support (positive confrontation)*
- *Discuss the metaphor of patient as the pilot/family as navigators*
- *Discuss co-dependency versus support (red flag: trying harder than s/he)*
- *Self-screen for family unmet needs (family meetings/huddle)*
- *Assertiveness with the medical team (communication wheel)*
- *Patience with bad days and canceled family plans*
- *Family/caregiver self-care plans*
- *Continued development of individual family members*
- *Family honesty and problem-solving*
- *Monitoring for depression*

CONSIDER THESE TYPES OF OUTCOME MEASUREMENTS TO ASSESS THE EFFECTIVENESS OF PHASE TWO INTERVENTIONS:

- Use verbal questioning as much as possible; patients burnout on all the surveys.
- Patient's and family's understanding of disease management
- Patient's perception of burden of adherence
- Secondary medical records (treatment counts/shortened treatments/fluid gains/BP/labs)
- Use formal depression screeners such as the Beck, PHQ-9, etc.
- Patient satisfaction with care instruments (CAHPS for in-center HD patients)
- Health-related quality of life survey scores
- Scaling questions where you can track and trend scores
- Patient daily/weekly record keeping (scaling)
- Marital/family scaling questions for comparison at point intervals

ADJUSTMENT: PHASE TWO

Case Example (Using the KDQOL)

Patient is a 52-year-old female who has been on dialysis for 2 years. She has a teenage son. She is a single mother and has worries about finances. She is currently on the transplant list. She is slightly overweight.

The patient completed the KDQOL-36 as part of the annual assessment and care planning process. The social worker entered the patient's responses into the free online scoring tool available at www.lifeoptions.org. This tool adjusts scores based on age (<45, 45-64, 65-74, 75+), gender (M, F), and diabetes status (Y, N). The social worker then discussed with the patient the following results -

- Physical component summary= 36.7 (average for dialysis patients her age without diabetes is 37)
- Mental component summary = 51.9 (average for dialysis patients her age without diabetes is 47.6)
- Burden of Kidney Disease score = 50 (average for dialysis patients her age without diabetes is 48.7)
- Symptoms and Problems score = 79.2 (average for dialysis patients her age without diabetes is 70)
- Effects of Kidney Disease score = 75.3 (average for dialysis patients her age without diabetes is 61.3)

The social worker told the patient that higher values indicate better functioning and well-being on all scales of the KDQOL-36.

The social worker and patient developed the following care plan.

ADJUSTMENT: PHASE TWO

Case Example—Care Plan

PROBLEM	INTERVENTION	OUTCOME
<ol style="list-style-type: none"> 1. Results of health-related quality of life measurement as compared with others of her age, gender, and diabetes status on the KDQOL-36 Online website: <ol style="list-style-type: none"> a. Physical Component Summary (PCS) is (36.7/average is 37) places her at average risk of hospitalization or death b. Symptoms and problems score (79.2/average is 70) places her at average risk of hospitalization or death c. Effects of kidney disease on daily life score higher (75.3/average is 61.3) places her at average risk of hospitalization or death 2. Limited support system 3. Limited resources 4. Need for long-term planning and education regarding transplant 	<ol style="list-style-type: none"> 1. Encourage more activity. Connect with community center for yoga class. Begin a regular walking program with a friend and neighbor. Take line dancing lessons for exercise and socialization. 2. Collaborate with interdisciplinary team to provide education on fluid management, dialysis adequacy, care of access. 3. Encourage patient empowerment and active participation in her care. Educate patient about treatment options and encourage her to talk with her doctor, the home training nurse, and patients about peritoneal dialysis and nocturnal hemodialysis. 4. Refer to support class offered in clinic to create support system 5. Brainstorm ways to obtain a job that would not jeopardize her SSDI while attending college where she will prepare for professional career off SSDI. Discuss work incentives, education and job options based on her vocational interests and work history, and refer to local VR agency for assistance in applying for grants/loans for college and work study to supplement SSDI. 6. Provided education regarding transplant. Made referral to transplant center. 	<ol style="list-style-type: none"> 1. 6 month follow up of KDQOL <ol style="list-style-type: none"> a. PCS score improved 7 points to 43 with increase in physical activity. b. Symptoms and problems score improved 3 points due to decrease in fluid gains between treatments which led to decreased cramps during dialysis. c. Effects of kidney disease on daily life score improved by 2 points and patient has a hopeful attitude about her future with chronic disease now that she is working her long-term vocational rehabilitation plan. She has begun nocturnal home hemodialysis, has almost no diet limitations and continues to work to lose weight. 2. Finances are still limited, but slightly improved. Patient has applied for Section 8 housing with a 1 year wait. She is supplementing her income with a part-time work study program through her college. 3. Patient seems more open to support class and will consider next month's group. She is meeting people through her line dancing group and has started dating. This indicates further adaptation to chronic illness and openness to increasing support.

NEPHROLOGY SOCIAL WORK INTERVENTIONS ADJUSTMENT: PHASE THREE

“PHYSICAL DECLINE AND DEATH”

Phase Three Intervention Goals:

- * *Acceptance*
- * *Physical Comfort*
- * *Patient Direction of Care*
- * *Care Management*
- * *Emotional Endurance*
- * *Peace/Integrity*

SOCIAL WORK INTERVENTIONS:

- Exhibit your comfort emotionally in speaking with the patient about their recent hospitalization and loss of health. Ask the patient what they have struggled with most recently.
- Explain to the patient that, during periods such as this, you like to make sure you have helped him/her to have all his/her decision documents in order, in the event s/he loses the ability to focus on decision making. Ask him/her if s/he has a DPAHC and if s/he is comfortable with the way it is completed and the agent assigned. Offer to review the document with him/her. Use stories of other patients who were unable to have their wishes honored.
- Provide psychoeducation to the patient with regard to dealing with physical decline. Explain that s/he is likely to feel mixed feelings and be focused on his/her decline at the same time s/he is focused on waiting to get better. Let him/her know that s/he can discuss both feelings with you. Think of a time period from which to operate. Help him/her measure progress, what s/he can and can't do each day. Talk openly about it regularly. Ask about his/her concerns.
- Allow the patient to discuss the family reaction to his/her recent decline. Often family members sense the patient is letting go and put pressure on the patient to fight. That request of the patient can elicit many internal reactions that may or may not get discussed with the family. Ask the patient if s/he feels the family understands what s/he is going through.
- If the patient begins to discuss the possibility of not getting better and the option of terminating treatment, let him/her know that you are comfortable staying close to him/her while s/he sorts things out. Ask if s/he feels comfortable speaking about it on the treatment floor or if s/he would rather come to your office. Invite the patient to share what situations s/he would worry about living with most. Which situations s/he could not tolerate. Problem-solve any unrealistic fears to the best of your ability to help the patient in his/her anxiety.
- Do not be afraid to acknowledge that what the patient fears seems real if they do. Stay honest, encouraging the patient like when s/he started dialysis, not to make any quick decisions. Don't assume patients can't handle the discussion. If you get uncomfortable, be honest with the patient. Tell him/her you just had a reaction to the thought of losing him/her. It helps him/her practice talking about things with his/her family. Stay close.

- Ask the patient's permission to speak with his/her physician about your conversation, especially if s/he has avoided being honest with him/her about thoughts of termination. It may be important for the physician to make sure his/her complaints are fully evaluated medically before assuming nothing can be done to make the patient more comfortable.
- Ask the patient about his/her spiritual views toward death. Be prepared to offer to connect him/her with a spiritual guide or minister of his/her choice to provide spiritual counseling.
- Get to know your physicians on this issue. What are their thoughts, feelings and preferences about how they would like these situations to be managed? How can you work together in the patient's best interest?
- Help the patient experience all of his/her feelings. Spend time on what s/he fears. Then ask him/her to spend time on the feeling of impending relief, and then on any shame that may exist about his/her decision, etc. Multiple feelings are often present and it can be very useful to help the patient identify and express them.
- Become comfortable in not guiding the patient. Explain that you just wanted to come by and sit with him/her for a few minutes and see if there was anything on his/her mind s/he wanted to talk about.
- Consider offering more of your time to do life review, journal for the patient, help write letters to his/her family about things s/he would want them to know, or complete an ethical will. These can be very healing instruments in the final stages of life.
- Help the patient prepare to talk with the family about this stage of decline. What would s/he want them to know? What does s/he need from them? Look for the following themes:
 - *Concerns with being a burden (suggest family self-care plans)*
 - *Fear of family reaction to decline and death*
 - *Fear of dependency and loss of control*
 - *Fear of nursing home placement*
 - *Fear of suffering/physical pain*
 - *Sadness about missing future events*

WORKING WITH THE FAMILY OF THE DECLINING ESRD PATIENT

- Remember that you are bound by confidentiality to the patient. Let the family member know they or you must seek the patient's permission to discuss his/her specific situation. This avoids harmful "secrets" and triangulation, and prevents you from carrying the emotional message for the parties. You may talk with the family and answer general questions about coping with declining health, the process of choosing to terminate treatment, the possibility of referral for hospice services and palliative care.
- Use the family's "secret" approach to encourage a dialogue meeting where you could be present to assist with communication. Explain to them how that might go.
- Don't assume the family can't tolerate the pain. Be calm and present yourself in order to communicate your comfort with talking about the patient's decline.
- Be prepared to have a nurse answer any medical questions for the family about the fear

of sudden death.

- Be prepared to answer questions about Hospice and other termination of treatment options.
- Ask the patient and family what they hope for during this last period of their time together.
- Discuss any advance directive documents that are in place so family is informed of them.
- Be prepared to refer family to a mental health provider if needed for additional counseling support to prepare for losing the patient.
- Be prepared to help the family and patient discuss patient's preferences for dying and funeral services. This is a good time for the family and patient to discuss spiritual views and preferences together.
- Provide support and direction at the end of the family meeting. These meetings are emotionally draining. If the patient has decided to terminate, ask him/her to guide the family in what s/he needs. If the termination decision is on hold, help the family discuss what they will do now to enjoy each other now that this discussion has taken place. Live "wide".
- Be prepared to make a home visit to help with a last minute decision about whether or not to come to dialysis (also to help bridge the hospice team into the patient's home).
- Be prepared to attend the funeral if you want to or have worked closely with the patient and family.
- Be prepared for a thank you call or perhaps a question from the family following the patient's death. Usually they want to talk a bit about any remaining feelings (regrets/hopes/remembrances).

SUPPORTING YOUR TEAM

- Remember that your team may have very different values and views toward termination of treatment. They may show their discomfort by avoiding the patient or any discussion of the issue. These are very personal areas we must all sort out. Allow the staff member space for his/her own views and feelings.
- Don't assume that your nephrologist doesn't struggle with these issues. Let him know you were concerned that s/he be aware of the discussions our patient is requesting to have with you and ask him to inform you of any concerns about the situation or professional preferences. This usually opens the dialogue between the nephrologist and the SW.
- Offer to hold a brief team meeting regarding a patient's decision to terminate for any staff that would like to attend. Give them a chance to discuss how it has affected them and any concerns, regrets, hopes.
- Help the staff live in the middle between the patient's living and the patient's dying if s/he continues dialysis. Be prepared to explore the following things with the staff:
 - *Their concerns regarding comfort management*
 - *Their values regarding his/her decision (cost of treatment/difficulty of care)*
 - *Their fear of his/her decline*

- *Their questions about whether they could have done something else that would have improved his/her status and changed the decision*
- *What they would like him/her to know.*
- If the patient arrested in the clinic, offer to help debrief staff regarding any remaining tensions or feelings about that experience and help them prepare to answer questions that might be asked by other patients.
- Consider helping your team say goodbye to patients or groups of patients with the following rituals:
 - *A monthly candle lighting for all the patients lost that month, with either their pictures or their names cut out on pieces of paper near the candle. You can also leave a page entitled "I'll remember....." for them to write on.*
 - *Allow the team to sign sympathy cards for the family.*
 - *Acknowledge the team's care of the patient in a staff meeting.*
 - *Consider a peaceful meditation reading about the importance of the team's work and a reading of the names of patients who have died at monthly staff meetings.*
- Help the team prepare to talk to other patients who ask about the patient's death. Things to consider:
 - *This is a delicate issue, and one that most clinics respond to by asking questions directly about the death and its cause.*
 - *Legally, it is a good idea to ask the family's permission to release that information and for the permission to provide funeral information to staff or other patients who request it. However, it may not always be possible or there may be no family.*
 - *Encourage staff to avoid releasing any further information other than what is needed for the general comfort of the patient asking.*
 - *Help staff prepare to respond to "Is that going to happen to me?"*

CONSIDER THESE TYPES OF OUTCOME MEASUREMENTS TO ASSESS THE EFFECTIVENESS OF YOUR PHASE THREE INTERVENTIONS:

- Scale (0-10) the patient's sense of comfort or peace with the issue.
- Scale (0-10) the family's sense of comfort or peace with the issue.
- Scale (0-10) the patient's and/or family's perception of how care management is going in the home environment.
- Scale (0-10) the patient's comfort in working with you on the issue.
- Scale (0-10) the staff's anxiety and grief before and after a support meeting.

ADJUSTMENT: PHASE THREE

Case Example (Using the KDQOL)

Mr. E is an 82-year-old male who began hemodialysis at age 76. He used a stationary bicycle twice daily every day he was not hospitalized. He has recently been diagnosed as needing an amputation. He and his wife have discussed that he no longer wants to dialyze. These thoughts are consistent with his recent KDQOL scores which were:

- Physical component summary = 16 (average for dialysis patients his age with diabetes is 31.9)
- Mental component summary = 53.5 (average for dialysis patients his age with diabetes is 42.8)
- Burden of Kidney Disease score = 0 (average for dialysis patients his age with diabetes is 36.8)
- Symptoms and Problems score = 72.9 (average for dialysis patients his age with diabetes is 73.2)
- Effects of Kidney Disease score = 62.5 (average for dialysis patients his age with diabetes is 68.8)

ADJUSTMENT: PHASE THREE

Case Example – Care Plan

PROBLEM	INTERVENTION	OUTCOME
<p><i>Patient has declining health and wishes to withdraw from dialysis treatment.</i></p>	<p>These scores, along with social work assessment, indicate that Mr. E is able to make a competent decision about withdrawing from treatment. The social worker discusses his and his wife's concerns with his nephrologists and a meeting is set up with the patient, spouse, social worker and doctor.</p> <ol style="list-style-type: none"> 1. Following meeting, the social worker refers the patient to hospice after explaining hospice services and assuring them that the dialysis center staff will remain available to them to assist with any questions and support needed. 2. The social worker has already provided an in-service to the staff about end of life care and reinforces this learning with staff, providing them with an opportunity to write a note in a card to Mr. E and his wife to say goodbye. 	<ol style="list-style-type: none"> 3. Patient has a positive end of life experience with hospice care, pain management and spiritual support. 4. Family feels supported by dialysis team in caring for patient during end of life. 5. Dialysis team understands that end of life care is important and appropriate in caring for dialysis patients.